

Candidate pack

Head of Governance and Compliance

Working towards a world free from MND



About MND and the work of the Association

Motor neurone disease (MND) is a fatal, rapidly progressing neurological condition affecting more than 5,000 adults in the UK at any one time. The disease causes messages from nerves (motor neurones) in the brain and spinal cord that control movement to gradually stop reaching the muscles, leading them to weaken, stiffen and waste.

The result is that people become locked in a failing body, unable to move, talk and eventually breathe. Some may experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia. MND does not usually affect senses such as sight, hearing and touch.

MND kills a third of people within a year and more than half within two years of diagnosis. It affects people from all backgrounds and a person's lifetime risk of developing MND around 1 in 300. Today six people will be diagnosed and six will die from MND. There is no cure.

The MND Association focuses on funding research, improving access to care and campaigning for people living with or affected by MND in England, Wales and Northern Ireland. We have over 11,000 members forming a powerful network that provides information and support for people with MND, their families and carers. We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure. We campaign and raise awareness so the needs of people with MND are recognised and addressed by wider society.

People with MND, their families and carers are at the heart of everything we do



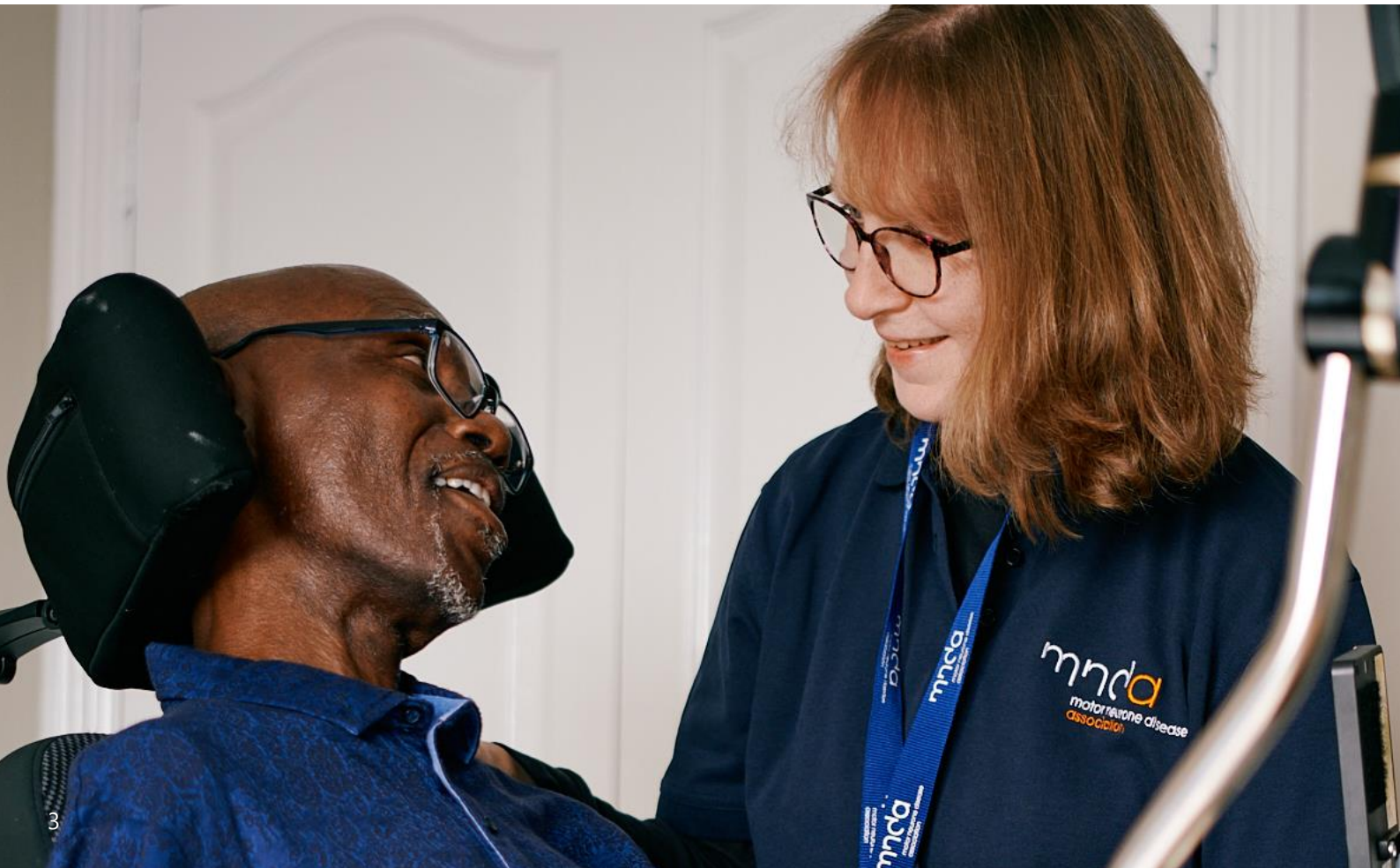
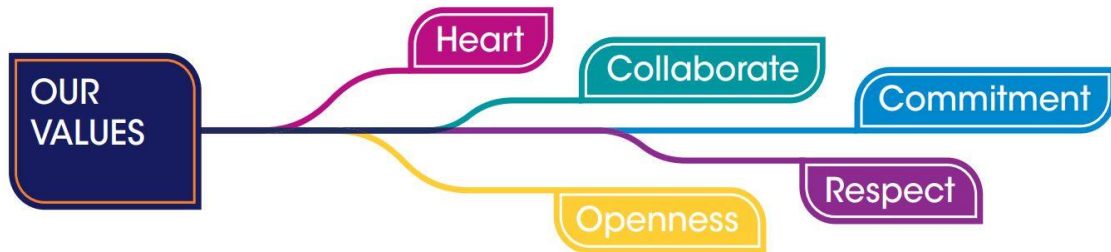
Our vision and Values

Our vision

A world free from MND.

Our Values

- People with MND, their families and carers are at the **heart** of everything we do.
- We **collaborate**, and value everyone's contribution.
- We achieve excellence through personal **commitment** and ongoing improvement.
- We **respect** and respond to people's diverse needs, backgrounds and views.
- We achieve our aims through building **open** and transparent relationships.



Our Promises

To harness the hope within our community to speed up progress towards a world free from MND, the MND Association has committed to five Promises. Our Promises give us focus to work faster and fight harder to strive for better – together with our community. Simply put, they drive everything we do.

Promise 1 We will not rest until: MND is treatable and ultimately curable

We are seeking new collaborative drug discovery and development projects, helping to fund and facilitate the research that is taking us ever closer to uncovering the causes of MND, effective treatments and ultimately a cure.

Promise 2 We will not rest until: Everyone gets the care they need when they need it

Co-ordinated multi-disciplinary care is the very best way to ensure a person with MND has access to all the healthcare professionals they need, at the right time. Our 22 care networks across the country provide this. But not everyone with MND has access to the same level of support. That must change.

Promise 3 We will not rest until: Every day with MND counts

For people with MND, technology can help life be the best it can be. We are working with tech giants from around the world to find solutions to real-life problems.

Promise 4 We will not rest until: You are heard

If we shout louder and to the right people, things will change. If we all join together we can't be ignored.

Promise 5 We will not rest until: No one faces MND alone

We will work to break down barriers that prevent people with and affected by MND from accessing the help and support they need.



Job Description

Job Title: Head of Governance and Compliance
Reports to: CEO
Direct Reports: One direct report

Job purpose

- Ensuring the MND Association has excellent and transparent governance and leadership policies, practices and ways of working which ensure that the MND Association has a high-performing executive function and is well positioned in a changing external environment reducing the MND Association's exposure to risk.
- Responsibilities of acting as the Associations Company Secretary.
- Providing support to the Chair, Board of Trustees, CEO and Executive Leadership team to develop the ongoing effectiveness of the Board, enabling it to provide the strategic oversight required as the Association evolves.
- Drive innovation and a culture by identifying, developing and championing improvements to processes and procedures, ensuring good Governance across all our working practice.

Main responsibilities

- Leading the governance function within the MND Association to ensure that it places high emphasis on the charity's governance practices, providing guidance and advice to the CEO, Chair and Board on associated issues.
- Taking a leading role in managing the relationship between the Board, its committees, and the executive and, as part of that, providing secretariat services to the Board of trustees and its committees to ensure compliance with legal and regulatory standards and the Association's constitution.
- Develop and implement corporate governance and risk policies, systems, framework, procedures, and events for the Board of trustees and its committees. Support the development and delivery of the Association's activities and ensure they are properly reviewed and maintained.
- Advising the Board and its committees, the Executive Leadership Team, and others on risk management as well as legal, regulatory and best practice requirements. Maintain a robust awareness of changes in legislation and provide appropriate advice to the Chair, Chief Executive and Board to ensure flexibility and innovation are balanced against core/ non-negotiable compliance requirements.
- Ensure that the quality and style of Board and Committee papers supports an agile and strategic focus which facilitates effective decision making.
- Support the identification of trustee learning needs and the delivery of tailored solutions.

Main responsibilities (cont)

- Complaints handling on behalf of the Chief Executive/Chair of the Association.
- Responsibility for the accurate and timely filing of accounts and reports at Companies House and Charity Commission, along with the reporting requirements for the Trading subsidiary MND sales company.

Governance

- Facilitating, and supporting the Chair and the CEO in relation to ensuring, a constructive but challenging relationship between the Board, Chair, and the Executive Leadership Team (ELT).
- Responsible for the functional development and delivery of excellence in governance that supports the delivery of the charity's strategy.
- Provide counsel and advice to CEO and Chair on, and playing a lead role in managing, corporate wide and/or sensitive issues related to the charity's governance, including issue management and the handling of developing risks.
- Working with a high degree of autonomy and executive judgement in the performance of complex tasks at the request of the Chair or the CEO, particularly where required to manage or reduce governance-related risks.
- Prepare papers and reports on key governance and corporate policy matters as required.
- Ensure that committees of the board are properly constituted with clear terms of reference.
- Provide effective support for committee business including preparation of papers, draft minutes, recording of actions and briefing members.
- Support the ELT collectively and individually in relation to the Board, including support and advice in relation to strategy, content and presentation of Board papers.
- Minute every meeting of the board and its committees as required, recording decisions, and following up any subsequent actions.
- Responsible in putting Governance expertise into the planning and execution of the MND Association AGM, and other Board or governance events.
- Report on governance performance to the Chair, CEO, Board of Trustees and ELT, making recommendations for improvement, and implementing agreed reforms.
- Develop systems to monitor and evaluate governance quality and standards across the MND Association.
- Lead in the ongoing recruitment, election or selection, induction of new Board members, ensuring succession planning in line with terms of office. To lead on the development of the board of trustees, ensuring the collective board and individual trustees are fully able to meet their roles and responsibilities.
- Develop and agree a plan and budget for the corporate governance function as required and properly report and evaluate on progress.

Main responsibilities (cont)

- Provide technical advice and support on governance matters and issues to the organisation, colleagues and others as required.
- Develop and maintain effective communications with members, staff, and other stakeholders on governance issues.
- Keep under review all external corporate governance developments and trends which might affect the MND Association and ensure that the board is fully briefed on these matters and have regard to them when taking decisions.
- Ensure that the MND Association is at the leading edge of transparent, accountable governance through continual professional development, networking and partnering.

Company Secretary

- Ensure the MND Association meets all its regulatory and reporting requirements to the charity regulators in the UK and Companies House.
- Ensure that the annual reports and annual returns are submitted to the charity regulators and Companies House on or before submission deadlines.

Compliance

- Lead on maintaining the register of corporate policies for the MND Association. Ensure they are of the highest standard, meet organisational and business needs and are governed to ensure they are always accurate and in date.
- Ensure MND Association rules and standard operating procedures, schemes of delegation and other governing documents are adhered to, regularly reviewed, and updated as necessary.
- Create a risk management framework that sets out the Board's risk appetite and ensures that risks are managed through effective and proportionate mitigation strategies at every level of the organisation with the appropriate integration so that the Board, through its committees, is aware of the key organisational risks.
- Create and implement sustainable systems for record keeping and information retrieval to comply with agreed governance standards and current regulation.
- Provide the Executive and the Board with effective legal Governance advice through access to a comprehensive legal service provider.
- Ensure that the Comments, Compliments and Complaints policy is regularly reviewed, and procedures are up-to-date.
- Working with the EA to the CEO, lead on the conduct of enquiries and complaints as required according to policy and procedure, working in partnership with appropriate staff.
- Propose and be accountable for the efficient management of Governance expenditure including effective budget preparation, planning, monitoring and review. Ensure effective financial and resource management.

Main responsibilities (cont)

Other duties

- Be prepared to travel to meetings across the UK and be away from home overnight, as the job reasonably demands.
- Undertake any other works as could be expected of a Head of Governance and Executive Office.
- Undertake any other task relevant to the job purpose and ensure that all functions performed reflect the Associations mission and core values.

Essential criteria

- Track record of effective working with boards and senior managers and the ability to manage sensitive and confidential information.
- Experience of presenting complex issues and reports to meetings at Board level.
- Excellent report drafting, communication and listening skills, to engage a diverse range of audiences.
- Ability to advise, guide, train and support colleagues and the Board on their legal, regulatory and ethical responsibilities and duties in a membership organisation.
- Knowledge of charity and company law and the regulatory requirements of a charity.
- Excellent time management, planning and prioritisation skills.
- Ability to form excellent working relationships - particularly in dealing with sensitive issues.
- Ability to work on own initiative with high degree of autonomy and executive judgement.
- Leading by example, encouraging and role modelling transparency, learning from failure, reducing complexity, user centricity, seeking feedback and ideas from all and using expertise from within.
- Communicating through a variety of approaches and tools.
- Learning through peers and experimentation, sharing the results and learning from them.

Salary: Circa. £62,000 per annum on a full-time permanent basis.

Location: Northampton Office with travel requirements to London

Hybrid Working Expectations: minimum 2 days per week office attendance (Flexibility to attend the office more regularly on occasion may be required to meet business needs.)

Pension

The option of the Auto Enrolment Scheme where the employee and employer both contribute 4% of your monthly salary, calculated after tax and national insurance (NI) have been deducted or an Enhanced Salary Sacrifice Scheme where the employee contributes a minimum of 5% and the Association contribute 8.1%, calculated before tax and NI are deducted.

Annual leave

28 days of annual leave, which increases by one day for each full calendar year worked, up to a maximum of 33, in addition to the recognised bank holidays.

Additional Benefits

- UK Healthcare: We provide level 1 cover, which reimburses healthcare costs including dentist, optician, health screening, specialist consultation and much more. Discover more [here](#).
- You and your household have 24/7 access to GP appointments, prescriptions and advice, all at no extra cost. Discover more about GP24 [here](#).
- Access to a confidential counselling helpline. Support for your health and wellbeing, including challenges related to family, work, finances and health.
- My Healthy Advantage: Access to the wellbeing app providing interactive tools to support your health and wellbeing.
- Salary sacrifice schemes include:
 - Save money and spread the cost of a new bike whilst reducing your carbon footprint.
 - Buy and sell up to 5 days annual leave.
- Life assurance: additional financial protection for your loved ones, ensuring piece of mind and a secure future.
- BenefitHub: Save money on your everyday shopping with access to 100s of high street discounted vouchers and offers, including cash back plans.
- Opportunities for training and personal development.

How to apply

Please submit a CV and supporting statement via our [website](#). This ensures your application is processed correctly and we have all the required information.

Your supporting statement should be no longer than one side of A4 and demonstrate how you meet the following areas of the role:

- Experience of the corporate governance function, preferably in a membership organisation or charity/charitable company.
- Track record of effective working with boards and senior managers and the ability to manage sensitive and confidential information.
- Experience of developing corporate policy and effective systems in support of organisational objectives and activities.

Where experience is asked for, please give one example showing what you did and what it achieved. Where we require evidence of ability, please explain either how you would approach that particular competence or give an example to support your suitability.

Please note, adverts may be closed before the deadline if sufficient applications are received. To avoid disappointment please apply early.

All applications will receive a response once shortlisting has been completed.

Inclusive recruitment

We are committed to providing people with disabilities an opportunity to compete fairly for jobs.

- We guarantee interviews for disabled applicants that meet the requirements of the role as part of our commitment to the Disability Confident Scheme.
- We can provide reasonable adjustments throughout the recruitment process.
- We communicate with applicants in a way that works best for them to ensure a positive and supportive candidate experience.

Alternative application process

To support an inclusive application process, we are open to receiving alternative applications from candidates who may find it difficult to complete our online form. If you would like to apply via video or audio file, please send your recorded application - ensuring you cover the supporting statement aspect - to HRRecruitment@mndassociation.org

Privacy Policy:

The information provided to the MND Association when applying for a vacancy will be treated in full accordance with the General Data Protection Regulation (GDPR).

The MND Association is committed to protecting your personal information and being transparent about what information we hold, whether you are a donor, volunteer, shopper, campaigner or a person living with or affected by MND.

For more information, visit [Privacy Policy | MND Association](#)

Right to work:

If you are successful in securing a role at the MND, you will be asked to produce your valid right to work documentation as part of our pre-employment checks. To find out more please visit our [website](#).

DBS checks:

Depending on the nature of your role you may be required to complete a criminal records check with the Disclosure and Barring Service (DBS).

Animal testing statement:

Research using animals has led to a greater understanding of MND. Because of the complexity of MND, at the moment animal models are still one of the most powerful tools used to help us understand, prevent and one day cure MND. Many of the achievements that stem from research funded by the MND Association, and by other organisations worldwide, would not have been possible without animal research. Even so, a great deal of our research is carried out without involving animals.

Any decision to use animals in research is never taken lightly. We understand that not everyone agrees with animal research. For more information, visit [Animal research | MND Association](#)

Looking out for our people

The wellbeing of our staff is very important to us, and that's why we've developed a wellbeing offer and programme of activities. These include:

- Mindfulness sessions
- Wellbeing sessions
- Menopause support group
- Parent and carer support group for children who are neurodivergent
- Less visible disabilities and conditions forum
- Mental Health First Aiders who provide support and signpost you to further information.

Learning and development opportunities

We understand the importance and benefits of continual learning. To facilitate your professional and personal growth, we provide a:

- comprehensive induction programme
- range of courses available on our Learning Management System - *Learning Lab*
- job shadowing policy, enabling you to strengthen your knowledge in other areas
- chance to study for an apprenticeship alongside your role.



Our commitment to inclusion

Motor neurone disease doesn't discriminate, and neither do we.

We are determined to become fully inclusive by continuing to embrace diversity, remaining committed to equity and ensuring that our products and services are fully accessible. In this way, we can ensure that **all** people living with and affected by MND get the best possible care and support they deserve.

We offer a variety of network groups and forums that are open to everyone, including our staff, volunteers, people living with and affected by MND, as well as Association members. These groups provide peer-to-peer support, raise awareness, and hold the Association accountable.

We are a Stonewall Diversity Champion, have recently been awarded Disability Confident-Employer status, and are members of the Communications Access Scheme.



Take a look at the [inclusion pages](#) on our website to learn more about our inclusion strategy, see how far we've come and where we are headed.



Where we work

Our central office is situated at Francis Crick House in Northampton, Moulton Park. It's a bright and modern space with a variety of flexible working spaces, meeting rooms, and communal areas.

We also have an office space in London, which is used predominately by our External Affairs Team. Some of our staff are based regionally and work from home.



Francis Crick House

Motor Neurone Disease Association

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6 Summerhouse Road Moulton Park,
Northampton NN3 6BJ
Tel: 01604 250505

MND Association

FORA
180 Borough High St,
London,
SE1 1LB



Francis Crick House



Our history

On 6 October 1979, three independent regional groups set up by people affected by MND came together for the first time as the MND Association. Professor Stephen Hawking accepted an invitation to be the Patients' Patron and remained a figurehead of the Association until his death in 2018.

Within a year, we had funded our first full time research fellow, based at Charing Cross Hospital's neurological department, and just two years later, in 1982, 40 specialists attended the Association's inaugural research conference.

Today, the Association funds the coordination of life-changing care for people living with MND and wide-ranging support for families and carers. We invest millions of pounds every year in the global research effort to discover the causes, potential new treatments and ultimately a cure for MND.

Visit our [website](#) to learn more about motor neurone disease and the important work we're doing at the Association.





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